

Mini Review

Providing Patients with Dementia and Neurological Diseases a Dignified Peaceful Demise

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Abstract

Taiwan enacted the Patient Self-Determination Act in January 6, 2016. It allows patient at 1. Terminal stage disease, 2. Irreversible comatous state, 3. Persistent vegetative state, 4. Severe dementic state, 5. Intolerable pain, incurable disease without adequate solution under the current medical standard, the right to withhold or withdraw whole or part of the life sustaining treatments. The Taiwan Neurological Society announced suggestions for withholding or withdrawal of futile life sustaining treatment for end stage neurological diseases. We hope to ensure a dignified and peaceful demise for patient at end stage dementia and other neurological diseases.

Keywords: Hospice Palliative Care, Patient Self-Determination Act, Hospice Palliative Care act, Advance Care Planning, Peaceful Dying, Good Death, Patient with Dementia, Dementia, Clinical Dementia rating, CDR, Do no Resuscitation, DNR.

Preface

In 2000, Taiwan established her Natural Death Act by the name of "Hospice Palliative Care Act" (HPCA) [1]. It allows the terminal patient to have the right of refusing cardiopulmonary resuscitation (CPR) by signing advance directive of Do no resuscitation (DNR). The Act was revised 3 times until 2013 [2]. For further expansion of the scope of Advance Care Planning, Taiwan launched a new law of "Patient Self Determination Law" on Jan. 6, 2016 [3]. This paper will introduce the scope of the new law and discuss about how we can provide dignified and peaceful dying for the end stage patient with dementia and/or other neurological diseases by this new law.

Hospice Palliative Care Act (HPCA)

The Hospice Palliative Care Act (HPCA), Taiwan's Natural Death Act was first announced in 2000 [1]. It received 3 revisions to reach the current issue of 2013 [2]. The Act gave our people the right to sign an advance order of DNR to ask physicians to withhold or withdraw cardiopulmonary resuscitation (CPR) at the terminal stage [1, 2, 4]. 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 care in any clinic or hospital. The Act defines "terminal stage" as when the patient is judged by 2 specialist-board certified physicians that he/she will eventually die in short period in spite of any medical care given. The duration is judged to be around or less than 6 months. It covers patients suffering from terminal stage of cancer, amyotrophic lateral sclerosis, AIDS, and terminal major organ failures. However, patients suffering from irreversible coma, permanent vegetative

state and severe dementia, are not covered by this Act owing to the undetermined length of survival.

Advance Care Planning (ACP)

Advance care planning (ACP) and advance directives (AD) are widely promoted in many western countries. The Patient Self-Determination Act (PSDA) was passed by the United States Congress in 1990. Effective on December 1, 1991, this legislation required many hospitals, nursing homes, home health agencies, hospice providers, health maintenance organizations, and other health care institutions to provide information about advance health care directives to adult patients upon their admission to the healthcare facility [5, 6]. England followed in 1995 [7]. And European countries in 2009 [8]. In Taiwan, ACP gradually came into the hospice palliative care movement after the passing of HPCA in 2000.

Patient Self-Determination Act (PSDA) of Taiwan

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" [9].

Ms. Yu-Xing Yang, a legislator (senator) and her husband, Professor Hsiao-Chih Sun of the Department of Philosophy, National Taiwan University joined the hospice palliative team of Taiwan to launch legalization of Patient Self-Determination Act (PSDA) in 2013 in promotion of the quality of terminal care of Taiwan [10]. Together we succeeded to pass the PSDA at the Legislative Yuan (the Senate) at the end of 2015 [3].

This Taiwan PSDA allows patient at 1. Terminal stage Disease,

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2. Irreversible Comatous State, 3. Persistent Vegetative State, 4. Severe dementic State, 5. Intolerable Pain, incurable disease without adequate solution under the current medical standard, the right to with hold or withdraw whole or part of the life sustaining treatments (Article 13) [3,10].

Patient with Dementia and Clinical Dementia Rating

There are several rating methods available for evaluating the severity of dementia, including the Mini-Mental State Examination (MMSE), the Wechsler Adult Intelligence Score (WAIS), the Cognitive Abilities Screening Instrument (CASI), and the Clinical Dementia Rating (CDR). The CDR developed by Hughes et al provides a global rating of the degree of dementia [11]. It uses CDR 0.5 (equivocal), CDR 1 (mild), CDR 2 (moderate) and CDR 3 (severe) to describe different degrees of dementia. For better definition of patient from CDR 3 to the end of life, CDR 4 (profound) and CDR 5 (terminal dementia) was developed [12]. A Chinese version was used in Taiwan by Lin and Liu [13]. CDR 4 (profound dementia) includes patient with severe impairment in language or comprehension; inability to walk unaided (mostly wheelchair bound); problems in feeding themselves and recognizing their family, controlling bowel or bladder function. CDR 5 (terminal dementia) includes patients requiring total care because they were completely uncommunicative, bedridden, vegetative and incontinent.

Ethical Issues in the Care for Dementia Patients

Since Taiwan has entered the stage of aging society and the number of patients with dementia (PWD) increases rapidly. Health care for patients with dementia has become important medical and social problems. Tsai et al [14] examined the ethical issues arising from the treatment and care for dementia patients including: drug therapy, participation in clinical trials, informed consent, medical decision making, genetic testing, terminal care, family and social support etc. The deterioration of brain functions finally influence on the limb-body movement and swallowing functions. The difficulty in feeding and swallowing causes repeated infections which are the usual cause of death for these patients. When is the appropriate time for providing hospice care for patients with dementia is a common dilemma for the medical personells. Mitchell at al [15] suggest that for the severe dementia patients who are bedridden with problems of fever, infection and feeding difficulty are appropriate time for discussing hospice care. About 40-50% of these patients are going to die within half year. Hongs et al [16] propose that it is appropriate time for starting palliative care when dementia patients lost the ability of self care and facing the need of acute medical treatment.

Palliative Care for Terminal Dementia

In response to the questioning by the Ministry of Health and Welfare (MOHW) the Taiwan Neurological Society made a suggestion or guideline for her fellow members about when to provide palliative care for terminal dementia patients and terminal neurological diseases [17]. When the dementia patient reaches the terminal dementia stage (CDR 5), he/she is bedridden with contracture of all limbs. No more futile life-sustaining treatment

is recommended. "The life-sustaining treatment for terminal neurological diseases" is defined as those treatments or measures can be used for maintaining the vital signs without effect of curing and can be used only for prolonging death. These include endotracheal tube, hemodialysis, peritoneal dialysis, second line or beyond antibiotics, surgical treatments. For the terminal dementia patient and terminal neurological disease patient, no more dialysis is recommended. If the patient suffers from pneumonia or other infections, only first line antibiotics are used. If the patient develops surgical complications, such as gastric perforation, intestinal obstruction or bleeding hemorrhoids, only conservative medical treatments are recommended. Hospice palliative care should be given for providing the patient a dignified and peaceful demise [17, 18]. When the Patient Self-Determination Act is effective 3 years later, [3] the patient with dementia and other terminal neurological diseases reaching CDR 4 and 5 may be eligible for consideration of withholding or withdrawal of life-sustaining treatments such as artificial feeding through tubes according to the advance directives given by the patient. Thus the length of suffering can be shortened and peaceful dying can be provided for these patients.

Taiwan Coma Scale

The Glasgow coma scale (GCS) proposed by Teasdale and Jennett [19] was widely used in Taiwan for making quantitative measure of coma. However, the GCS made the lowest scale to 1 for those "none" responses in eye (E), speech (V) and limb movement (M). The total lowest scale is 3. The family in Taiwan usually felt that there might be some hope for the scale of 3, and continued to wait for miracle to occur. It costed the patient to suffer from the continual torture of the futile medicine. I had suggested using a Taiwan Coma Scale (TCS) which lowers one point for each item of GCS. This would make the lowest point of the "none" response to 0 [20]. When the scale reaches 0, it might be easier to persuade the family members for discussion about withdrawal of the futile life sustaining treatment. Hope this will further improve the quality of hospice palliative care in Taiwan. Hope this will help those with irreversible coma to have a shorter stay in Intensive Care Unit and to have a more peaceful passing.

May all physicians make the following wish while making their routine practice: "May all my patients be cured of physical pain and mental suffering, obtain peace and happiness, have a healthy body and harmonious mind, practice all good deeds, achieve final peaceful path to the Heavenly Kingdom of God or Buddha's Pure Land."

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