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*Even though January 6, 2020 was a Monday, the lobby of Taipei Main Station was full of people. Why were they there? They were there for the experiential game booths such as Life Autonomy Monopoly and Patient Autonomy School. As they watched and participated, they also burst into laughter by these fascinating games, which were designed with the purpose of familiarizing them with patient autonomy. Through these fun activities, they gained awareness of a peaceful option at the end of life.*



On the first anniversary of the implementation of the Patient Right to Autonomy Act in Taiwan, the Hospice Foundation of Taiwan organized a special press conference and consultation called My Medical Treatment, My Decision in order to guide more people to understand the importance of hospice care and dying well.

# Patient Right to Autonomy Act in Effect for Its First Year

## Number of Enrollees Exceeds 10,000

At the press conference, Dr. Cheng Shun-Ping, Secretary General of the Ministry of Health and Welfare, presented awards to the leading hospitals in 20 cities and counties as well as to the Patient Autonomy Research Center and the Hospice Foundation of Taiwan, in appreciation for their efforts in promoting the Patient Right to Autonomy Act. He noted, "The Patient Right to Autonomy Act was passed only one year ago, and it has already produced good



results." Dr. Cheng pointed out that there are currently 140 medical institutions and more than 1,000 clinical staff who have completed training and joined the Advance Care Planning (ACP) service; thus far, they have assisted 11,240 individuals to complete the signing of their Advance Decision (AD).

From the perspective of front-line medical staff, such achievement has been a breakthrough. The President of Taipei City Hospital, Huang Sheng-Jian, who has long promoted the concept of hospice care and dying a good death, revealed that between 2007-2009, the number of enrollees of the "Advance Hospice Palliative Care and Life-Sustaining Treatment Choices of Intent" (DNR) increased from below 4,000 to over 10,000 after only one year since the Patient Right to Autonomy Act started. He says, "This increase in enrollments shows the Taiwanese people's awareness of a good death is growing, and this year alone, Taipei City Hospital has received more than 2,000 enrollments of Advance Decision. Additionally, we clearly see the growth and expansion of the medical team in this area."

# Medical Paradigm Move Towards Value-Based Health Care

Yang Yuh-Hsin, the CEO of the Patient Autonomy Research Center, is also known as the Angel of Rare Disorders because she suffers from a rare muscle disease called Miyoshi myopathy since the age of 19. As a patient herself, she is qualified to express the importance of ACP and the need for Taiwan to have a good mechanism for people to learn how to make meaningful medical decisions. She explains, "These decisions must be empowered, that is, patients must clearly understand what the medical conditions are, evaluate their various interests and values, and thereafter, make a consensus decision with their families." Because the patients have made their ADs, there is harmony in their relationships with family and doctors rather than allowing pressure to remain on them, which could sometimes cause disputes. "This, too, is part of the shift in medical paradigm" says Yang Yuh-Hsin .

As Taiwan has become an aging society, there are still many issues that need to be resolved, either in terms of the awareness of health or of dying well issues. Huang Shier-Chieg, Director of the Taipei City Health Department, says, "Currently, people's knowledge regarding death and dying well is still insufficient. Thus, over usage of medical resources or ineffective medical treatments still occur in clinical caring. Even if these are not the original intention of medical treatment, patients and their families are often troubled under the existing system."



"Death is something everyone will encounter. There are still many challenges to overcome and everyone needs to work together on improving the quality of life of patients." Therefore, Huang Sheri-Chieg believes that the first anniversary of the Patient Right to Autonomy Act is precisely the best time to conduct a comprehensive review. Thus, combined experiences and brainstorming by experts from all parties over the past year will help the Patient Right to Autonomy Act progress more smoothly.

# Is it Easy to Sign and Difficult to Implement? Clinically Full of Challenges



To this end, on November 30, 2019, the Hospice Foundation of Taiwan gathered medical and legal professionals to hold a Patient Right to Autonomy Act Dialogue and Practical Care Strategies.

On the topic of Clinical Challenges of a Physician's Obligation in Interpretation, Hsieh Wan-Ting, the Director of Chi-en Hospice Ward of Chi Mei Medical Center, stated, "Although life and death issues are important, they are not easy to talk about." After 2005, the relationship between doctors and patients has gradually shifted from patriarchy to autonomous decision-making. As such, in clinical practice, what doctors should say and how to say it is full of challenges.

"The point is, after talking about life and death with the patient, what happens afterwards?" Hsieh Wan-Ting believes that patients should be provided with professional medical prognosis along with alternative medical options. More importantly, patients must be allowed active participation in these decisions; therefore, patient autonomy should not have only two options: agree or disagree, but rather, even after patients choose to disagree, the medical team should further understand the reasons and explain the results of non-treatment.



# Learning from Foreign Cases

## Ponder on the Positioning of Medical Designated Agents

To further protect patient's medical rights, the Patient Right to Autonomy Act has added the role of designated medical agent. The patients' designated agents can express or make medical decisions on their behalf when they are unable to express their wishes. Chen Chih-Hsiung, the Director of the School of Law at National Chiao Tung University, gave his professional legal opinion on "the influence of medical designated agents and relatives on the practice of a patient's autonomy."

Chen Chih-Hsiung cited an example from the United States. The basis for the US court to judge a patient's possible wishes should be: whether it is said in a serious occasion, whether it is repeatedly expressed, and whether this willingness is consistent with the patient's values (such as religion), and so on. American non-profit organizations also developed a set of patient's Letter of Intent. If the patient is unconscious from the beginning (such as a vegetative person) or is a minor, there are alternative judgment standards. However, if they disagree with their parents, the court will usually continue the treatment as death is irreversible. Nevertheless, such judgments may also lead to a controversy that "may underestimate the suffering caused by life-sustaining treatments."



Chen Chih-Hsiung said that because expressing medical willingness is only a right rather than an obligation, in practice, the designated medical agent may be unwilling to express opinions or cannot be contacted. Thus, items entrusted by a

patient's designated medical agent cannot be implemented. In the United States, all medical personnel or family members can serve as supervisors for designated medical agents. Therefore, he suggested that Taiwan can refer to the establishment of a supervisory appeal mechanism, so that the law can effectively intervene when disputes occur.

# Implementing the Spirit of the Patient Right to Autonomy Act

## Respect for Patient Autonomy

On the topic of Switching from Advance Decision (AD) to Physician Orders for Life-Sustaining Treatment (POLST), Huang Sheau-Feng, a physician in the palliative care unit of Taichung Veterans General Hospital, presented clinical challenges that have been brought forward by the Patient Right to Autonomy Act. The more common problems seen included ambiguous implementation details and skills used in communicating with the family members who disagree with each other.

Huang Sheau-Feng said, "AD was designed for patients to have a say and express their wishes during medical consultations. Once the requests of the family members are found to be different from that of the patients' own, the team must first fully clarify the expectations of the family members, and then follow up with attentive communication." He also revealed that it is often very difficult for family members to make the decision to "remove life-support equipment" so it may be wise to communicate step-by-step in order to let the family members have consensus on the removal. Thereafter, observation indicators ought to be set up within a time frame.

Huang Sheau-Feng provided an example. A terminal-stage patient who had refused life-sustaining treatment, artificial nutrition and hydration changed his mind during the treatment process. He noted, "The decision made at that time should override the previously written decision. Thus, the medical team needs to complete the AD change for the patient."



## 30 Years of Hard and Hearty Work For All the World to See Taiwan

Yang Yuh-Cheng, Chairman of the Hospice Foundation of Taiwan said, "The Patient Right to Autonomy Act still has a long way to go from implementation to perfection. There are still many areas we need to put effort on to improve. However, what we do today will help ensure protection for ourselves and our loved ones in the future." This not only benefits our own rights, but also demonstrates the paradigm shift in Taiwan's medical culture and human rights.

The Hospice Foundation of Taiwan spared no effort to give impetus to the Patient Right to Autonomy Act in ensuring people's right in dying well. Since 2016, the foundation has undertaken relevant programs of the Ministry of Health and Welfare and started various tasks. In addition to public education, the foundation has also started training courses to train ACP counselors and to counsel hospitals in opening consultation clinics. Currently, many hospitals in all counties, cities, and even surrounding islands provide ACP consulting. Clearly, the foundation is providing ubiquitous assistance to help all Taiwanese to accept the idea of dying well.

The Ministry of Health and Welfare also announced earlier this year that 11 rare diseases, including cystic fibrosis and Huntington's disease, will be included in the Patient Right to Autonomy Act, in which the patients can terminate, withdraw or refuse life-sustaining treatment and artificial nutrition and hydration. This inclusion will affect an estimated 32,010 patients.

Yang Yuh-Cheng indicted that due to the unremitting efforts of the past 30 years, "We can proudly say Taiwan's medical standards and human rights in terms of hospice care and quality of death are exemplary to the world." We are sure that Taiwan can continue to set a positive example for others to follow and for more patients to benefit.



# Reflecting on Advance Care Planning (ACP) from the Heart

*To further train and improve upon Taiwan's hospice and palliative care, in February 2020 the Hospice Foundation of Taiwan organized a delegation of medical professionals to visit Japan and exchange experiences of Advance Care Planning (ACP) and hospice knowledge.*



Following Taiwan's Hospice Palliative Care Act, the Patient Right to Autonomy Act—the first patient-centered legislation in Asia—launched in early 2019 which extended the scope of hospice care. Not only applicable for terminal cases, the Patient Right to Autonomy Act allows any person who has specific clinical conditions the right to express his/her own willingness to receive hospice care.

Neighbouring Japan has promoted home medical care and hospice for many years already, and only recently, has started to encourage ACP (which is also called Life Meeting and Advance Directive in Japan). In order to acquire a diversity of thoughts and ideas on the Patient Right of Autonomy Act, the Rotary Club of Osaka Umeda and Rotary Club of Taipei Tienmou worked together to assist the Rotary International Foundation to hold the Global Awards and Professional Service Training Project. They appointed the Hospice Foundation of Taiwan to lead a professional medical team to areas in Japan where ACP is practiced, including Seirei Mikatahara General Hospital, Kameda General Hospital, Hamamatsu City, and Tochigi City. Team members also attended a seminar held by the Japan Association for Clinical Ethics.

# To Legislate or Not? Different ACP Approaches in Japan and Taiwan



In 2019, there were 28.4% of the Japanese population (or around 35,880,000 people) who exceeded age 65; this makes Japan the most aged society in the world. The challenge to take care of this aging population increases as Japan is vast in territory with a dramatic gap between the urban and rural residents. To cope with the rapid aging population, Japan developed a long-term home medical care system in 1980, and focused on those areas where general medical care is lacking. This policy created a strong doctor-patient relationship and helped the local government to promote ACP by assisting patients to spend their last days in familiar surroundings.

Dr. Chun-Kai Fang, the Director of the Hospice Foundation of Taiwan and also the leader of the delegation to Japan, noted that although both Taiwan and Japan promote ACP, these two countries' approaches differ in significant ways. On the one hand, Taiwan has legislated the Patient Right Autonomy Act to protect patients after they have signed the Advance Decision (AD); on the other hand, Japan utilizes ACP through an ethical lens and encourages local government to promote ACP through the home medical care system.

These two different approaches were developed in large part to complement the two countries' different medical systems. Taiwan has excellent medical care

accessibility and health insurance coverage. As a result, it regulated the Hospice Palliative Care Act 20 years ago in order to guide health care personnel when they provide services and to protect patient rights, thus preventing unnecessary medical disputes. However, as Vanessa Lin, CEO of Hospice Foundation of Taiwan, carefully observes, “Japan considers the dying process a natural human right, which is not necessary to legislate. Even if there is legislation, how could it be tailored to fulfill each case’s unique needs?”

Besides the legal aspect, the forms of applying ACP also differ between these two countries. In Taiwan, the government formulates AD as an unifying legal document, allowing patients to sign AD after receiving ACP to ensure their legal right to receive hospice care. On the other hand, Japan authorizes local governments to promote their localized versions of ACP. Although the entire ACP process has no legal binding, local governments serve the same purpose to communicate effectively with patients and families about dying well and the value of life.

For instance, Japan’s Shizuoka Prefecture’s Hamamatsu City uses the Naotora diagram<sup>1</sup> to illustrate the entire process of ACP, including: emergency contact information, various medical decisions at different stages of diseases, location where patients wish to pass away, funeral arrangements, and etc. The Naotora diagram is intentionally simple and clear in order to easily lead the prefecture’s patients through their end-of-life issues step by step.



Various local governments and organizations in Japan have launched similar promotional materials. Some use local historical figures like the Naotora diagram (also known as the Life Meeting Notebook); others translate the America Coda Foundation’s Go Wish Card into the Japanese language.

Certainly, the materials may be different, but they have the same purpose to guide people to think more deeply about their lives and life decisions.

<sup>1</sup>Naotora diagram (直虎表): Ii Naotora is a historical person in Shizuoka Prefecture. The local Japanese government utilizes this cultural identity to better promote the important policy among the local people.

## Connected to Home Medical Care, ACP Can Embrace Different Forms

During this visit, team members noticed these two countries have different approaches and mindsets regarding ACP and hospice. “There are both pros and cons, but what we learned most is how to reach a balance between ethics and law on the complicated life issue,” says Dr. Chun-Kai Fang.

Vanessa Lin mentioned that the Patient Right to Autonomy Act has been in effect for over one year, and medical staffs have encountered challenges while applying it. For instance, before visiting Japan, the Taiwan delegation tended to focus more on how to adapt to the regulations of the Act, “but now we have to think outside the box, and consider this issue from the ethical side.”

In Japan, ACP is not limited to hospital premises, and there is no need for regulations in providing consultation or signing the contract; rather, ACP is merely a process to assist patients towards hospice care. It is also not something that needs to attain specific results, not something that can be quantified.

As an example, Vanessa Lin cites a medical team in Tochigi City. This group is composed of pharmacists, nutritionists, nurses, physical therapists, dentists, and specialized medical officers. For over a decade, they have conducted home medical care for patients. Besides their daily work, the team provides household visits whenever there is a need; therefore, they have established a good doctor-patient relationship, which allows them to easily and naturally start the ACP conversation and help patients embrace hospice care.



## Pondering Life Issues from an Ethical Perspective

Life is full of difficult choices, and Japan is dealing with how best to provide ethical hospice care in the least harmful way for patients.

During the visit, the Japan Association for Clinical Ethics hosted a two-day seminar, which included a discussion about a dementia



patient who received ACP. This patient was part of a small family, and after some time, the family members became exhausted in doing the caring themselves that they admitted the patient to a nursing home. However, they did not tell the patient the truth about the circumstances. In the end, the patient was unable to adjust to the new environment and ran away from the nursing home.

The lecturer used this example to let the team reflect upon the Four Ethical Principles: Autonomy, Beneficence, Justice, and Nonmaleficence. In this case, the family could no longer bear the burden of care for the patient, and the patient ran away after they sent the patient to the nursing home because his personal will was not considered. In other words, the patient was ignored on an ethical level. The question remains: How to balance ethics and reality among the family, the patient, and the institutional staff?

The lecturer led the team to analyze the case by examining the ethical viewpoint. “Through this activity, we are reminded that each case is unique, and we have to consider every aspect before assisting patients and their families in making an appropriate decision,” said Ching-Ping Liu, the Director of Hospice Foundation of Taiwan.

Under such a thorough process of thinking, Japan has developed different guidelines to suit various ACP types. For example, medical staff can follow the Dementia Care Guideline to conduct ACP when dealing with dementia patients; it assists the medical staff on how to perform ACP without compromising patients’ right to decision making.

Compared to Japan, Taiwan's medical care rings a busy and rapid tempo. The medical staff is used to seeking the most efficient and effective medical practice, especially under complex situations. "However, within the rapid process, we may unintentionally overlook key details and patients' rights; this is where we need to pay much attention to," said Ching-Ping Liu.

## Pondering the Significance of ACP from the "People" Perspective

Taiwan launched the Patient Right to Autonomy Act over a year ago, and many hospitals have since started ACP consultation clinics. Thus far, over 10,000 people have signed up for AD. Dr. Chun-Kai Fang believes that although ACP has legal status in Taiwan, it is too focused on signing contracts and completing regulations. Instead, effective hospice care also needs complementary measures which are not currently being fulfilled. Although Japan has not legislated ACP, Japan does combine the existing home medical care with ACP so that its system is more holistic than Taiwan's.

During this visit to Japan, one important insight gained is that signing the AD should start from creating a long-term relationship between the medical staff and patients. The service can be extended from the hospital into the community, which helps to bridge general care to long-term and hospice care. Certainly, this insight will help Taiwan to complete a more perfect long-term health care network.

Both Ching-Ping Liu and Vanessa Lin had mentioned that through this visit to Japan, our medical staff members have had the chance to rethink the true value of ACP. That is, when providing consultation from the people's perspective, it may be helpful to downplay the forms and regulations, and instead, to focus on communicating and discussing the value and significance of life. After all, that is the original intention for the legislation of the Patient Right to Autonomy Act.