

Hospice
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Forever Love, Endless Care

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BRINGING HOPE — TO THOSE IN DESPAIR — 1-4 AUGUST 2019, SURABAYA-INDONESIA

APHC 2019 *Bringing Hope to Those in Despair*

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[...more](#)



Learning from Each Other by Improving Domestic Hospice Capabilities

[...more](#)



Moving Forward to Becoming the Asia-Pacific Learning Model

As palliative care continues to advance

[...more](#)



Early Intervention Assists in Returning to Society

Faced with the difficult problems of children's palliative care, Fang Junkai, Director of the MacKay Hospice and Palliative Care Center in

[...more](#)



Learn from Others - Palliative Care in Hong Kong

Not only does Taiwan offer thoughts about itself and for the future, but Amy Chow, a professor with social work background, also shares

[...more](#)



Mandarin Speaking Hospice Summit in Asia-Pacific - Spread Love Regardless of National Differences

[...more](#)

Hospice Foundation of Taiwan
www.hospice.org.tw

No. 45, Minsheng Road, Danshui District, New Taipei City 25160 Taiwan
Tel: +886-2-28081130 Fax: +886-2-28081137 E-mail: hospice@hospice.org.tw

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Multiple Countries Cooperate to Establish Harmonious Movement in Palliative Care

The 13th Asia Pacific Hospice Conference (APHC) was successfully concluded in Surabaya, Indonesia in early August. However, the effects of the conference continue to ferment in the hearts of hospice staffs in Asia Pacific.

This year, the biennial Asia Pacific Hospice Conference (APHC) held its 13th conference and opened a number of palliative care seminars under the theme Bringing Hope to Those in Despair.

In addition to leading domestic hospice related personnel to the grand event, Wang Yingwei, Director of the Health Promotion Administration at Taiwan's Ministry of Health and Welfare and also an APHC director, has also contributed many thoughts and reflections through his participation at the conference.



Learning from Each Other by Improving Domestic Hospice Capabilities



"In fact, palliative care in many countries has been done very well, and each has its own attributes; as a result, each has something that we can learn from," says Wang Yingwei. He further analyzes that, for a national policy or similar systems, Taiwan's palliative care ranks among the best among Asian countries. "However, at the level of personal care, we still have lots of improvements to make. For example, Japan has many favorable intentions and innovative aspects that we can learn from."

Overall, Wang Yingwei is most impressed by the palliative care of Singapore. During the early stages of Taiwan's promotion of non-cancer palliative care, Wang Yingwei felt that Singapore was more advanced in this aspect, and invited Singaporean experts to speak in Taiwan. One expert told him that Singapore obtained experiences from the United States when they first started, "But later on, they [US] invited me over to share our experiences regarding palliative care in community development. They learned quickly, and even combined the Advanced Care Planning (ACP), from general to individual needs. Over time, Singapore's palliative care has become complete and also humane."

Adapting Training Methods to Local Conditions for Effective Results

Modesty leads to progress. Due to its early start and comprehensive support in policy and law, Taiwan has developed quite rapidly in enhancing palliative care and has become the model for many countries.

As a member of the Education Committee of the Asia Pacific Hospice Palliative Care Network (APHN), Wang Yingwei represented Taiwan at a APHN meeting in the belief that it is necessary to adapt the education and training of palliative care to local conditions. He says, "I have been to some developing countries before, and found that the developed countries and developing countries have very different ideas about palliative care; their medical environments are completely different as well." Wang Yingwei explains that policies and medical environments vary among countries. "We've talked about the use of morphine and painkillers, but there were no similar drugs available locally. There's no use for them then to come learn from us. For example, some foreign students came to Taiwan for training. We taught them to use computer tomography, but they were correct to point out the fact that only their capital city has such equipment, and the remote areas where they are located do not have these at all. Thus, even if they learned these computer skills, they have no way to apply it in their countries."

"The most important thing in teaching, actually, is to learn rather than teach. Support is what we need to offer each other," continues Wang Yingwei. He then uses a seed illustration, saying: if there is no soil and no water, even if there are seeds readily available, these seeds cannot grow. Therefore, when seed training is required, we should first prepare the soil and water. Additionally, we need to understand the nature of the seeds by assessing what they need and building a supportive network for them. Ultimately, only with such efforts can the training can be effective."

"In the future, the biggest challenge that the Board of Education will face is how to use effective methods to impart experience and achieve the benefits of teaching and learning," concludes Wang Yingwei.

Moving Forward to Becoming the Asia-Pacific Learning Model



As palliative care continues to advance internationally, Cheng Yuyi, the attending physician of the Family Medicine Department at National Taiwan University Hospital, talks about the advantages of Taiwan's palliative care. He states, "Taiwan's palliative care is legally supported by the government, so we have no obstacles to hinder its development. In terms of drugs, many painkillers have been introduced in recent years allowing doctors to have more choices. As for others, whether it is hospitalized palliative care, home care, or combined hospital-home care, it is quite thorough in Taiwan. In conclusion, palliative care in Taiwan can be said to be truly complete."

For more than 10 years, Taiwan has implemented cancer control plans in accordance with the World Health Organization (WHO) regulations. It is hoped that patients will receive good and consistent treatment from cancer prevention and treatment to terminal-stage care. Adopting WHO's cancer control strategy has really allowed palliative care to bloom throughout Taiwan. For instance, more than 200 hospitals in Taiwan have signed relevant contracts with the Health Promotion Administration to integrate palliative care into regular cancer treatment.

"The National Taiwan University Hospital is required to have palliative care staff involved in at least 70% of all cancer patients' cases," Cheng Shaoyi says. This regulation to implement palliative care on cancer patients allows them to receive higher quality of care if they should face the last stages of life.

In addition, the ACP has been the highlight of this year's conference. With Taiwan being the first country in the Asia-Pacific region to implement the Patient Autonomy Law, many countries naturally have high expectations on Taiwan and are paying particular attention to Taiwan's developments. Currently, Taiwan is working with five other Asia-Pacific countries to develop the Asia-Pacific ACP Guidelines using family as the core concept. "Compared to countries such as South Korea, Indonesia, Japan, Hong Kong and Singapore, it is still only a vision, but we have already begun to draft the content of the declaration," says Cheng Shaoyi.



The Well Established Palliative Care Contributed by the First-Line Personnel

The success of Taiwan's palliative care development has largely been due to the improvement of policies and hardware equipment. However, Cheng Shaoyi, who has been devoted to palliative care for many years, stresses that the major contribution was made by the staff members of the palliative care facilities.

Cheng Shaoyi expresses the difficulties for outsiders to imagine that palliative care is often not a calm scene like those in the movies, but contains a variety of different challenges. "Palliative care is really a tough job. Many patients suffer from wounds and suppuration, and there may be a heavy odor in the air. Sometimes, a staff can take up to one hour just to clean up the wound."

She still remembers a patient with oral cancer, who stood at the door and whose sickly smell had spread throughout the ward. "Our caregiver spent several hours helping him clean the wound, apply essential oil, and finally restore the fresh scent back into the room. The patient was also able to rest comfortably."

Improvements Needed to Determine Palliative Care Transfer Status for Non-Cancer Patients

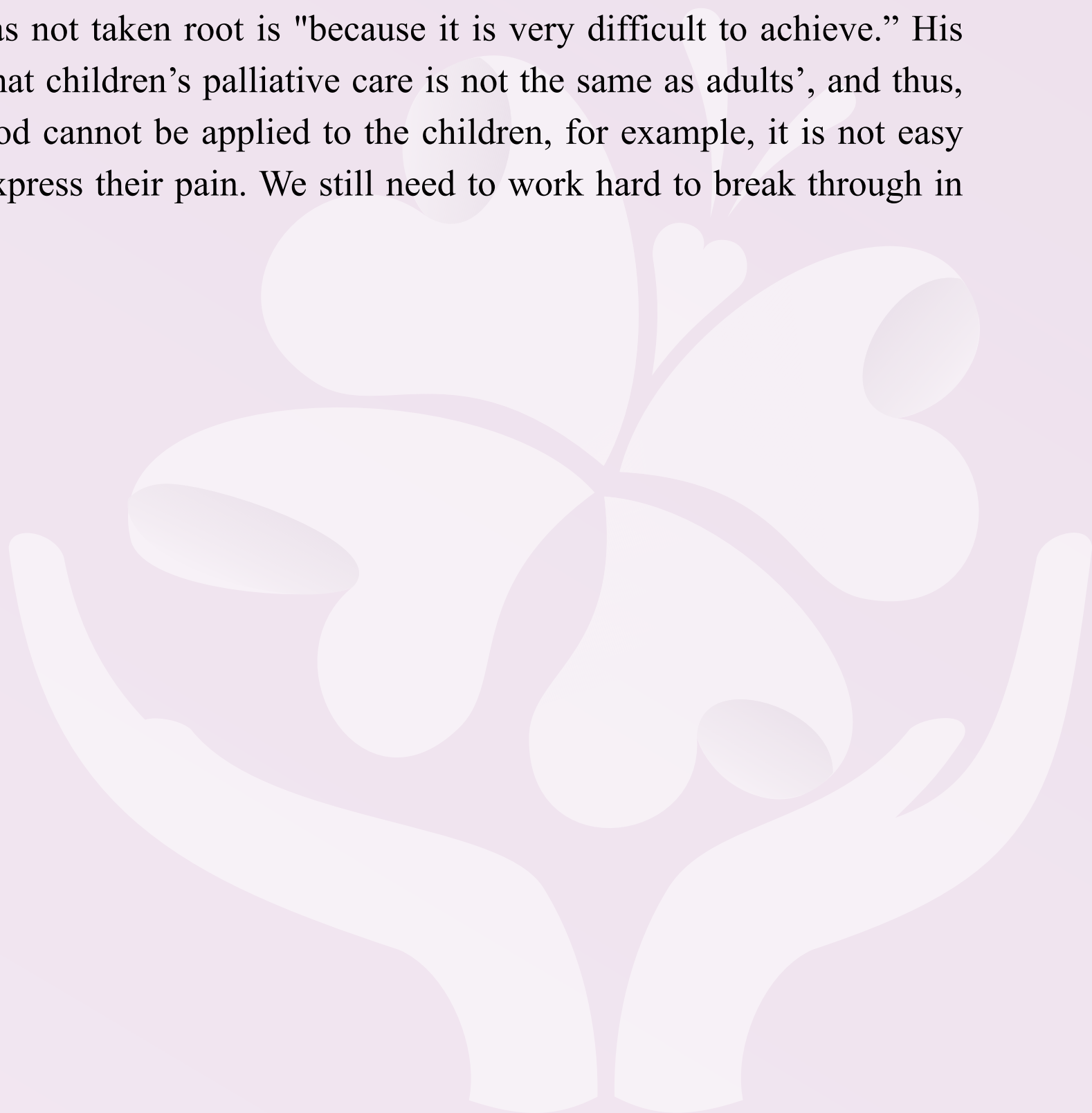
Taiwan's strength in palliative care is its dedication and loving care. However, even though the performance of Taiwan's palliative care already stands out

among countries in the Asia-Pacific region, Cheng Shaoyi believes that more introspection is needed in many aspects in Taiwan.

Taiwan Hospice and Palliative Medical Regulations became effective starting in 2000. In 2009, eight major non-cancer illnesses were included in palliative care, which is the first in Asia; most countries around the world have not even progressed to include non-cancer illnesses. Despite this, the number of referrals from non-cancer patients to palliative care in Taiwan is still limited "because there are difficulties," according to Cheng Shaoyi.

Cheng Shaoyi explains that the development of non-cancer illnesses is not as clear as cancer which can be differentiated into stages. Therefore, it is difficult for doctors to determine whether the patients have met the necessity for palliative care. For example, many bedridden patients with advanced dementia may need hospice intervention; however, the actual number of cases accepted to palliative care is very low. The same goes for patients with heart failure, cirrhosis, and etc., where boundaries between stages are vague, resulting in many patients who pass away before they could be transferred to palliative care facilities.

Another group of patients, who are late to enter hospice care, is the children. Therefore, this year's APHC Conference featured a series of lectures on the theme Children's Palliative Care. According to Cheng Shaoyi, the reason why children's palliative care has not taken root is "because it is very difficult to achieve." His analysis shows that children's palliative care is not the same as adults', and thus, "The same method cannot be applied to the children, for example, it is not easy for children to express their pain. We still need to work hard to break through in Taiwan."



Early Intervention Assists in Returning to Society

Faced with the difficult problems of children's palliative care, Fang Junkai, Director of the MacKay Hospice and Palliative Care Center in Taipei, and Cheng Shaoyi have the same reflection.

Fang Junkai notes, "In recent years, the development of children's palliative care has been very slow in Taiwan." However, after participating in APHC, he unexpectedly found that in countries where medical care is less advanced, the proportion of children's palliative care cases is quite high. "This is because better children's medical care leads to lower demand for children's palliative care. In addition, the medical team usually takes active treatments believing that children are still young and there's always hope."

From this, Fang Junkai began to wonder: "In our palliative care, we tend to estimate the time of intervention in relation to the last stage of the patient's illness. But how much sooner is the best time for us to intervene?" At this APHC conference, some other countries shared a refreshing view regarding when palliative care should begin, for instance, whether starting at the diagnosis of cancer or at the cancer screening.

"Nowadays, people diagnosed with cancer just live out the typical five years while expecting the cancer to recur. They don't work, they don't do anything, but live a handicapped lifestyle awaiting death. How many people's lives could have been enriched in those five years?" Fang Junkai believes that if intervention occurs too late in the process, especially when the survival rates of cancer patients are improving, it is actually equivalent to creating more people with physical and mental disabilities. With a smile, he ponders, "So, are the doctors really benefiting or afflicting the patients?"

In his research, Fang Junkai found that cancer patients who work are less prone to have dementia compared to cancer patients who do not work. As such, he believes palliative care should be introduced earlier for cancer patients. Along with the treatment, the patient can maintain the ability to work and also retain the value



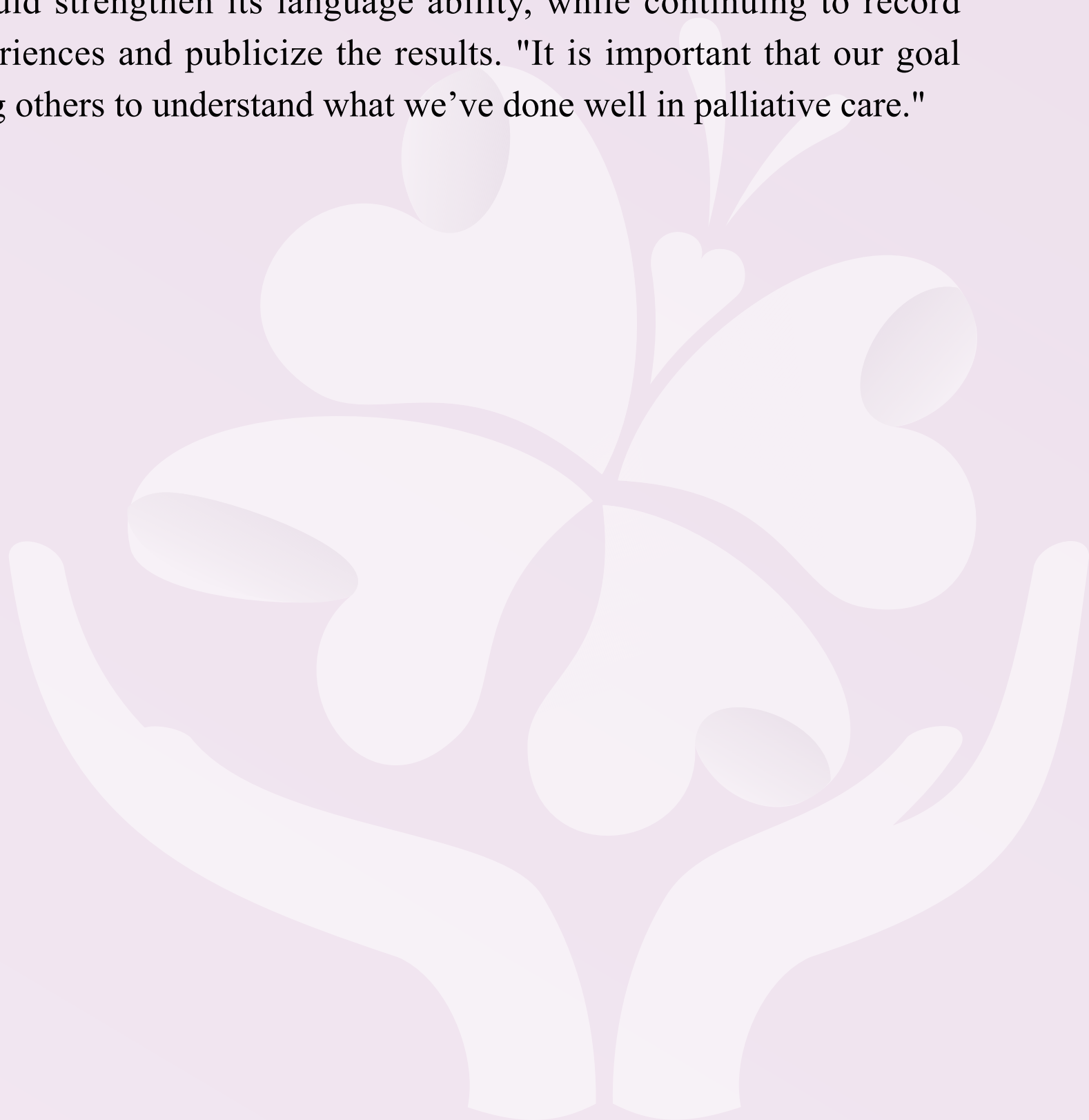
of life. He affirms, "The title cancer fighter sounds very powerful, but we should let the patients understand that they are not just cancer fighters, but they are still human beings with important roles to play in life."

Strengthening Language Skills by Promoting Taiwan's Palliative care

As one of the members of APHN council, Fang Junkai feels strongly whenever he participates in the annual APHC. He says, "In the field of palliative care, Taiwan is not inferior to the international community. The only disadvantage is that we are not an English-speaking country."

He points out that even if Taiwan is devoted to palliative care, it is difficult to be exposed internationally: "Foreigners may realize that we have great palliative care in Taiwan. However, they have relatively limited understanding of what we are doing because the papers we publish and the policies we launch are all in Mandarin. Not only are these hard to understand in English-speaking countries, but these are also difficult to be useful in teaching."

Considering the weakness of the language in research, Fang Junkai believes that Taiwan should strengthen its language ability, while continuing to record the clinical experiences and publicize the results. "It is important that our goal includes allowing others to understand what we've done well in palliative care."



Learn from Others - Palliative Care in Hong Kong



Not only does Taiwan offer thoughts about itself and for the future, but Amy Chow, a professor with social work background, also shares the palliative care challenges which Hong Kong is currently facing. She explains, "Palliative care in Hong Kong began in 1982 and has been progressing for 37 years now."

Furthermore, Hong Kong's palliative care began in the British colonial Catholic hospitals and slowly expanded to other medical institutions. Although it started out early, it was only until 1992 that it gradually flourished.

"That was the year when I started working," she says. Working in the field of palliative care for many years, Amy admits that her beginning knowledge came straight from textbooks. She still remembers the first time she led students into the medical institute for palliative care as a supervising professor of students, and how she had no relevant experience. Since then, she has realized one can only truly learn from doing. Because she saw this societal need, she courageously decided to continue.

Amy also recalls in her early days of palliative care, how she once met a pair of siblings in the hospital. The younger brother was a 30 year-old physics teacher who was at the terminal stage of liver cancer. Amy discovered that although the sister visited him at the hospital every day, the two did not speak at all. "Whenever the brother lies in bed, she would be sitting close by without saying a word."

One day, when the brother was absent, Amy went to talk to the sister, who immediately burst into tears. Amy says, "She [the sister] felt very guilty towards her brother because he loved literature but she had forced him to study physics. He was even held back a year once because of that decision. She thinks that this made her brother very unhappy and was the cause of liver disease. She felt very guilty for this, but does not know how to confess."

Later, Amy also talked to the brother alone, and told him about his sister's hidden guilt. The brother was shocked and told Amy, "No, it's my fault. My sister quit

school young to work and supported us in education. She also helped me make good decisions, including the opportunity to teach physics. I am proud of myself."

After understanding the confused yet caring hearts of both, Amy started a heart-to-heart dialogue for the siblings so that the sister could be relieved of her guilt. Soon after, when Amy passed by their ward, she occasionally heard lively conversation coming from the room.

Conversation Limited in Chinese Society - Learning from International Cases

"Hospice is not just to treat the bodies, but also to appease the hearts," says Amy. Since realizing this, she has been promoting related concepts in Hong Kong. However, she also realizes that the traditional thinking of Chinese culture slows down progress. "Many Chinese, especially older patients, are not used to talking about this topic, so we have to use various tactics and to include the family members to participate."

Besides accumulating knowledge within ourselves, Amy also believes that the successful experience of overseas countries has provided great help in the development of palliative care in Hong Kong. Especially in this APHC conference, she has seen many different possibilities.

Amy notes, "Every country makes different discoveries. Most developing cities emphasize clinical care, but mostly Chinese regions, such as Taiwan and Singapore, are more focused on psychological communication, especially how family members communicate and talk." On the other hand, she also observes that palliative care of non-cancer patients has gradually become a new trend. "This conference has lecturers who discussed patients with Alzheimer's disease and long-term kidney disease in palliative care. This is something that Hong Kong must learn from."

Mandarin Speaking Hospice Summit in Asia-Pacific - Spread Love Regardless of National Differences



Countries with similar cultures and the same languages can learn from each other for simultaneous growth. At the APHC conference, in addition to setting up a number of featured seminars related to palliative care, the highlight was the Mandarin Speaking Hospice Summit in Asia-Pacific .

As the host of the conference, Professor Lai Yunliang, who is the Honorary Physician of the MacKay Hospice and Palliative Care Center in Taipei and also the Director of the Hospice Foundation of Taiwan, traces the origin of the Mandarin Speaking Hospice Summit in Asia-Pacific to the 2015 APHC Conference held in Taiwan.

He says, "We felt that the Mandarin speaking participants expressed the most passion regarding palliative care. They were also particularly touched and responsive." Therefore, the first Mandarin Speaking Hospice Summit in Asia-Pacific was held at the 11th APHC Conference hosted by Taiwan in 2015. "The results were unprecedented. A total of 170 participants participated, and everyone was impressed."

This year, even when the Summit was held in non-Mandarin speaking areas, the number of participants reached more than 100. Lai Yunliang was especially happy to see that everyone continued discussions even during break times.

Lai Yunliang's expertise in this field creates strong feelings as he says, "The population of mainland China makes up more than half of the entire Mandarin language population. It is also a country that is in need of palliative care. They want to do it well, but they don't know how to proceed. As for Taiwan, palliative care has been developing for a relatively long period of time. Not only is there a clear model, but it is also well known and accepted among the Taiwanese community. It is standardized and systematized in many aspects. Through this conference, everyone learned from each other, shared their passion, and moved on together."

Lai Yunliang also reflects on the demand for palliative care. "From the perspective of palliative care, we can search for similar approaches through different opinions. As palliative care staff, when we see someone in pain, we want to approach the patient and help. The Mandarin Speaking Hospice Summer in Asia-Pacific participants have similar backgrounds and use the same language. Palliative care can be carried forward by people working together with mutual understanding." However, due to the international situation and Taiwan being a founding member of the Asia Pacific Hospice Palliative Care Network, reaching out to a non-member country such as China to join will be a challenge for the future.

Lai Yunliang believes that palliative care is like a Confucius proverb: "In spite of different opinions, gentlemen can get along with each other well." Lai Yunliang thinks that, "Although the Taiwanese and mainland Chinese come from different countries and have different accents, they can still make a concerted effort on behalf of the patients." Using another proverb, he further explains the current palliative care on the international level is like burning charcoals: "One charcoal will soon be extinguished, two charcoals will burn for a longer time, but a pile of charcoals will burn for a very long time. This is the strength of Mandarin Speaking Hospice Summit in Asia-Pacific. I am seeing many charcoals burning together."

May the enthusiasm for palliative care spread widely and have ripple effects. Hopefully, like music, more exchanges will be made among the hospitals and communities among the Asia Pacific countries in the years to come as they learn to play together the most beautiful movement of life.